GOVERNMENT OF INDIA
HEALTH AND FAMILY WELFARE
LOK SABHA

UNSTARRED QUESTION NO:2242
ANSWERED ON:28.07.2017
Thalassemia Patients
Adhikari,Shri,Dibyendu;Kamaraaj Dr. K.

Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

(a) whether the Government is planning for a National policy on thalassemia;

(b) if so, the total number of patients suffering from thalassemia in the country;

(c) whether it is also a fact that due to lack of access to treatment and the costs, a large number of people die across the country;

(d) if so, the details of services in the hospitals and allocation of funds by the Government towards gene therapy process therein; and

(e) whether the Government proposes to declare the patients of thalassemia as physically handicapped to give them access to various facilities like concession in rail/ bus fare etc. available to physically handicapped persons and if so, the details thereof?

Answer

ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND
FAMILY WELFARE
(SMT. ANUPRIYA PATEL)
(a): Public Health is a state subject. Under the National Health Mission (NHM), the Ministry has prepared and issued comprehensive guideline for Haemoglobinopathies (Thalassemia, Sickle cell anemia and other variant anaemia) for prevention and management of Haemoglobinopathies.

(b) & (c): The exact number of patients is not known. The estimated number of patients in the country is 100000 with addition of approximately 1000 new cases every year. Data available on population screening by National Institute of Immunohaematology, Mumbai under Jai Vigyan Project is annexed. No published statistics regarding the annual deaths due to thalassemia is available.

(d): Public health and hospitals is a State subject. Government has not allocated any funds separately for gene therapy process.

(e): The Central Government has enacted the Rights of Persons with Disabilities Act, 2016 which came into force from 19.4.2017. Thalassemia has been included as a specified disability under the said Act. The Act provides for various rights and entitlements for persons with disabilities such as equality and non-discrimination, protection from cruelty and inhuman treatment, reproductive rights, access to justice etc. Further the Act mandates the appropriate Government to frame schemes and programmes to promote social security, health, rehabilitation and recreation of persons with disabilities.